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ABSTRACT

Family caregivers may face ethical dilemmas when deciding whether a parent or spouse should enter a nursing home. There is considerable evidence that decisions about institutionalization are usually stressful and difficult for family members. This study obtained qualitative and quantitative data from two studies conducted at the Margaret Blenkner Research Center of the Benjamin Rose Institute to illustrate six ethical issues involved in family caregiving and institutionalization. The first study involved a survey of 614 family members living with and caring for an impaired elderly spouse or parent and a follow-up study 4 years later with 146 of the original families, 35 of whom had institutionalized the elder during that time. The second study was a 6-year panel study of family decision making and caregiving which involved 400 caregiving families, 32 of whom had institutionalized an elderly parent. Combining both studies, 67 families were interviewed before and after the elder's institutionalization. Results of the interviews revealed dilemmas arising because of: (1) difficulties inherent in defining what is best for the individual elder; (2) problems in delineating caregivers' responsibilities toward the parent or spouse; (3) conflicts of interest or competing obligations; (4) policies, services, and reimbursement mechanisms for long-term care; (5) tension between such values as autonomy and paternalism; (6) different perceptions among caregivers; and (7) the quality of family relationships. (Forty-one references are supplied.) (NB)

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Family Caregivers' Perspectives on Institutionalization Decisions

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Running Head: Family Caregivers

This article focuses on ethical dilemmas family caregivers may face in answering the question: should my parent or spouse enter a nursing home? These ethical dilemmas arise when caregivers confront a choice between equally unsatisfactory alternatives or when the justification for choosing one option over another is ambiguous, nonexistent, or contradictory.

There is considerable evidence that decisions about institutionalization are usually stressful and difficult ones, indeed, for family members. The choice has been described as a nadir of life, a last resort, and a family crisis (Brody & Spark, 1966; Cath, 1972; Townsend, 1964). Common reactions to a family member's institutionalization include feelings of guilt, anger, hopelessness, helplessness, failure, grief, loss, abandonment, and depression, combined sometimes with relief and acceptance (Brody, 1977; Greenfield, 1984; Kasmarik & Lester, 1984). In studies conducted by the Benjamin Rose Institute in Cleveland, Ohio, 57% of adult-child caregivers and 86% of spouse caregivers concurred that their elderly parent's or spouse's institutionalization was the most difficult problem they'd ever had to face; 69% of the children and 79% of the spouses also reported it was easy to feel overwhelmed by the elder's nursing home placement.

Furthermore, placement does not necessarily end family caregivers' quandaries about whether they've done enough for the elder or whether they've done the right thing (Hatch & Franken, 1984; Lynott, 1983). One daughter in our studies observed nearly a year after her mother's institutionalization, "I do my best to convince myself that this is the best and only answer to caring for my mother . . . I just wish I could do more for her . . . I keep thinking should I have done this . . .?"

The difficult, problematic nature of the placement decision is also evident from the tendency of many family caregivers to postpone or otherwise seek to

avoid this decision (Edelson & Lyons, 1985). As one son in our studies said prior to his widowed mother's institutionalization, "I may have to make a decision for which I'm not prepared." Given this tendency to postpone placement, institutionalization often occurs when the resources of both care recipients and care providers are seriously eroded (Brody, 1977; Edelson & Lyons, 1985; Kasmarik & Lester, 1984).

Studies of decisionmaking about institutionalization, from the family's perspective, are surprisingly few, usually retrospective and based on small samples, and they infrequently make ethical issues an explicit focus. Therefore, a great deal is still unknown about how, when, and why these decisions are made. Nevertheless, several ethical dilemmas can be extrapolated from studies of family caregiving and institutionalization. The six issues selected for this paper are meant to be illustrative, not exhaustive or definitive. Furthermore, in describing general concerns, we should not lose sight of the great diversity contained within broad categories such as family caregivers, elderly care recipients, and institutional care settings, as well as in the caregiving paths families have traveled before reaching the nursing home.

To illustrate these ethical dilemmas, this paper draws on both quantitative and qualitative data from two studies conducted at the Margaret Blenkner Research Center of the Benjamin Rose Institute. One of these studies was a survey of 614 family members living with and caring for an impaired elderly spouse or parent (Noelker & Poulshock, 1982). Approximately four years after the original survey, the Retirement Research Foundation provided funding for a follow-up study with 146 of these families. In 35 of the 146 families, the elder had been institutionalized during the intervening four-year period.

Our second study at the Rose Institute is a six-year panel study of family decisionmaking and caregiving, funded by the National Institute of Mental Health (NIMH) and begun in 1981. This study included a purposive sample of over 400 caregiving families in the greater Cleveland area, all of which included either a widowed mother age 60 or older living alone or a married couple both age 60 or older living together and at least one adult child living within one hour of the parent. Like the first study, this one was designed to include a variety of both types and degrees of physical and mental impairment among care recipients. Unlike the previous study, however, the NIMH project sought to interview all proximate adult children, as well as the care recipient and his or her spouse if married. In all, 32 of these families had a parent become institutionalized. Combining both studies, then, 67 families were interviewed both before and after the elder's institutionalization, and these are the families on which this paper primarily focuses.

Dilemmas Related to Beneficence

The first set of dilemmas arises from the ethical principle of beneficence, the delicate balance between doing good and avoiding or minimizing harm to the older person (Aroskar, 1980; Gadow, 1980). When family caregivers face the question of institutionalization, they are inevitably confronted with weighing the disadvantages as well as the advantages, the benefits as well as the costs, of both institutional care and other alternatives.

Compared to home care, for example, institutional care may have the advantages of being more reliably available (e.g., seven days a week, 24 hours a day), more extensive in the range of care provided, or more highly skilled in terms of both staff and technology. It may provide structure, protection, stimulation, or social interaction lacking in the home setting.

On the other hand, potential disadvantages to institutional care can be loss of privacy, of independence, of control over one's lifestyle and over what care is provided, when, how, and by whom. Institutional policies, philosophy and values, reimbursement mechanisms, and staff practices may compromise the quality of care provided. Even the best institutional settings can rarely duplicate the personalized care, emotional support, and affection believed to be the most distinctive, albeit often idealized, functions of family.

As McAuley and Blieszner (1985) and Shanas (1962) have documented, most community-residing older persons would prefer to receive care in their own home from either paid and/or family sources rather than nursing home care. But, for a variety of reasons, family caregivers often face the dilemma of how to honor this preference in the face of nonexistent, insufficient, fragmented, inconveniently structured, unreimbursable or costly community services. Although 98% of the family caregivers in our two Rose Institute studies agreed, after the elder's placement, there wasn't any other alternative, 85% also agreed there weren't many choices available about ways to meet the elder's care needs.

The ethical dilemmas family caregivers face are heightened by the fact that placement decisions, so far as we know, infrequently involve advance planning and discussion by family members, are often made in haste after a medical or other crisis, without extensive or well-informed consideration of alternatives, and frequently are influenced by factors other than the type or quality of care provided--factors such as the availability of a bed, the cost, or the facility's location (Brody, 1977; Knight & Walker, 1985; VanMeter & Johnson, 1985; York & Calsyn, 1977).

Decisions about institutionalization are further complicated for family caregivers because of many peoples' association of nursing home placement with

death (Gustafson, 1981). Whether implied through metaphor, as in the phrase "nursing homes are the end of the line," or explicitly stated, as when one of the adult children in our studies said, "(Being in the nursing home) is killing my mother," this pessimistic and terminal connotation adds an extra ethical burden to family caregivers' decisionmaking. Furthermore, by virtue of its institutional nature, nursing home placement may also conflict with caregivers' and/or elders' wishes about dying: for example, the wish to die at home, in familiar surroundings, or without intervention (Calkins, 1972; Chenitz, 1983).

Even when family caregivers do not equate institutionalization with physical death of the elder, placement may still, consciously or unconsciously, be interpreted as "social death" (Glaser & Strauss, 1968; Pace & Anstett, 1984). In part, this stems from public perceptions of nursing home residents as typically depressed, mentally impaired, apathetic, heavily sedated, and abandoned by family and friends (Brody, 1977; Tobin & Lieberman, 1976).

Thus, the question of whether an elderly parent or spouse should enter a nursing home is fraught with ethical dilemmas for family members seeking to do what is best for the elder, because of both the nature of the alternatives and the circumstances under which these decisions typically are made. For one thing, family members are usually confronted with choices which are counter to most elders' preferences and which necessarily involve some serious risks, disadvantages, or conflicts in values for the elder. Second, our programs and policies severely limit most families' options. Third, the likelihood of positive and negative outcomes are hard to predict, and families often must make a decision under conditions loaded with uncertainty. For example, several adult-child caregivers in our studies reported being pleasantly surprised when their parents' physical or emotional health improved after placement. As one daughter

reported about her institutionalized mother, "She can talk and see other people here and has improved so much I can't believe it." Other children were dismayed to discover how poor the care was in the nursing homes they had selected. Fourth, something which may be of benefit for one person may be of harm to another. Thus, the pros and cons of institutionalization versus home care and of one facility versus another depend in part on complex interactions among the elder's physical and mental condition, personality, values, and history.

Conflicting Obligations and Interests

While the previous set of dilemmas was characterized by conflicts due to the difficulty of avoiding harm for the elder, another set of ethical dilemmas arises in trying to balance the best interests of the elder with those of other family members. One of the most difficult of these dilemmas is the challenge of maintaining caregivers' physical, emotional, and social well-being while meeting the impaired parent's or spouse's need for care.

Evidence of caregivers' concern with this is reflected by the fact that 87% of the spouses and 67% of the children providing care in our original NIMH sample endorsed maintaining their own health and well-being as one of their goals. Many caregivers realize that this is essential to keeping the elder out of a nursing home. When asked in a prior study at the Rose Institute about the conditions under which they would consider nursing home placement, caregivers were much more likely to mention deterioration of their own health than that of the elder. Later analysis of families who actually did place the elder in a nursing home revealed that restriction of the primary caregiver's activities and poor physical health of the caregiver were significantly related to institutionalization (Deimling & Poulshock, 1985).

Family caregivers' ability to achieve this goal of maintaining their own welfare is often a tremendous struggle, however. Caregivers in our NIMH study whose elders were later institutionalized were three times more likely to report, prior to the placement, that caregiving had negatively affected their physical health and nearly four times more likely to report it had negatively affected their emotional health than comparable caregivers who continued providing home care. Data from other sources show similar findings: of 739 caregiving employees recently surveyed at the Travelers Corporation, 30% had not had a vacation from caregiving responsibilities in over a year (Collins, 1986).

One dilemma, then, is that caregiving in the community exacts a heavy physical, emotional, and social toll on some caregivers, particularly elderly spouses (Cantor, 1983; Noelker et al., 1984). Yet the caregiver's well-being is often a critical buffer between home care and institutionalization. Furthermore, the strain of caregiving sometimes erodes the affective bond between caregiver and care recipient (Poulshock & Deimling, 1984), and institutionalization may serve the positive function of improving or averting further deterioration of these relationships (Smith & Bengtson, 1979).

When the costs to caregivers' own welfare become too great and what weight to give caregivers' versus elders' well-being are very difficult issues for families to resolve. This dilemma is not one affecting families only. Those who design, fund, and provide services to families must also ask themselves how much they expect family caregivers to do, with what sacrifices, and with what support. For example, few opportunities currently exist for short-term institutionalization of elders solely to allow family caregivers respite to protect their own health.

Dilemmas related to conflicting obligations also arise when caregivers' obligations to the elder are antithetical to or incompatible with obligations to others. Such conflicts are particularly common for adult children. In our original NIMH sample, for example, half of the adult children selected keeping their own family life from being disrupted as one of their goals in caring for the parent. That this goal is not easy to achieve, however, is shown by the Travelers Corporation study, which found 80% of 739 employees saying that caring for an elderly person had interfered with other family responsibilities (Collins, 1986). Also, Noelker and Poulshock (1982) found evidence that caregiving stress was greater in three-generation households than in one- and two-generation arrangements.

In post-institutionalization interviews in our studies, conflicts between the parents' care needs and the adult-child caregivers' other responsibilities toward work, their own children and/or spouses, or elderly parents-in-law were mentioned frequently as one of the reasons for deciding on institutional care. These conflicts influenced placement decisions by increasing caregivers' sense of burden, by leading caregivers to reject some alternative care arrangements as infeasible, and by limiting caregivers' ability to successfully sustain the care arrangements they did try. For example, some families did not even consider living with the parent as an alternative to nursing home placement because of such competing obligations; others in our studies tried living together, but said it didn't work out for these same reasons.

These conflicting obligations can create great strain, fatigue, ambivalence, anger, and guilt for many adult-child caregivers trying to decide whether institutionalization is best. As one daughter in our studies said, ". . . we

never want (our mother) to feel we did what was easiest for us instead of what was best for her." Nursing home placement does not necessarily alleviate conflicts between obligations toward the parent and other responsibilities, however. After placement, 57% of the adult children (but only 29% of spouses) in our two studies reported feeling torn by such conflicting responsibilities.

When there is more than one child in a family, the dilemmas of defining, prioritizing, and balancing competing obligations become compounded, both because of the greater number of people involved and because of potential conflicts related to norms of fairness or equity. For example, adult children in our studies often reported difficulties getting other family members to cooperate in caring for the parent before placement or getting them to visit the parent after placement. Other research on adult-child caregivers has commented on the frequency with which one child assumes a disproportionate share of the caregiving burden, and the sense of resentment which can accrue when other family members are not perceived as carrying their fair share of the load (Brody & Spark, 1966). The added burden which such intrafamily tensions can add to institutionalization was expressed by one of the children in our studies who said: "My siblings give (their) time and care grudgingly. Affairs are handled, but not without complaints, blaming, and a 'Why do I have to do this?' attitude."

In part, the dilemma of balancing the caregiver's moral obligations to the elder, to the caregiver herself or himself, and to others stems from the many ambiguities and conflicting values embedded in family norms and expectations in our society, particularly for adult children (Lowy, 1983; Meier & Cassel, 1986; Wetle, 1985b), as well as from demographic changes, such as increased longevity and the growing numbers of elderly persons, of smaller families, of employed

women (Riley, 1983; Treas, 1977). There is little social consensus, and sometimes not even intrafamilial agreement, on the specific nature of family members' responsibilities toward elderly relatives, the limits of these obligations, or the balance to be struck between the best interests of individuals and intergenerational and family ties.

There are various subtle and not so subtle ways in which family caregivers' beliefs about their obligations toward the elder create ethical dilemmas when institutionalization becomes necessary. Many spouses in our samples, for example, described caring for the elder at home as a means of fulfilling their marital vows. As one elderly husband commented about his impaired wife, "She's my wife. As long as I'm here, I'll take care of her. Putting her in a nursing home would be a very last resort." Some children defined caring for the parent, despite great hardship, as a way of repaying the parent for earlier care. Other studies have reported instances where elders extracted promises from family members, sometimes years in advance, never to put them in a nursing home (Meier & Cassel, 1986; Pace & Anstett, 1984).

There are also other values besides those associated with family obligations which can create ethical dilemmas around institutionalization. For example, Cleveland is a city with many pockets of strong ethnic and/or religious identity. The Rose Institute's Community Services staff and some of the families in our studies have commented on ways in which traditional ethnic or religious values of taking care of one's own, of respect for the aged, of honoring one's father and mother can be interpreted by family members as injunctions to care for the older person at home. Also, for elders for whom ethnic or religious traditions give structure, meaning, and comfort in their lives, the dilemma of institutionalization becomes even more acute if facilities which

incorporate such traditions are not available. Conversely, some family caregivers in our studies reported that finding a nursing home with an ethnic or religious affiliation eased the placement decision.

Economic Dilemmas

In deciding whether, when, or where to institutionalize an older relative, family caregivers are often faced with dilemmas created by economic factors. One family in our studies, for example, had been looking into nursing homes for over a year before the actual placement but, as the daughter said, "The places we have looked into make us see that she could never afford this type of arrangement. So at this point we are really lost as to what we should do." One-third of the families in our two studies reported, after placement, that the cost of care at the facility was a problem.

Sometimes the cost directly conflicted with family preferences about the elder's care. In one case, for example, a daughter said both she and the parent were very satisfied with the care at the present facility, but the mother would soon have to move for financial reasons to a less costly one, where the daughter questioned the quality of care provided. In another family, an only son, who picked avoiding financial hardship as his primary goal after his widowed mother's institutionalization, said, "The home she is at is wonderful, but at around $1,800 a month it would soon break you, and I do have to think of my family."

For elderly spouse caregivers, the conflict between paying for nursing home care and having enough money to live on themselves is particularly poignant. The New York Times recently reported that some elderly wives are facing the dilemma of living in extreme poverty or suing their institutionalized husbands in court for support (Sullivan, 1986). Several of these wives saw this as such

an insult to their husbands and their marriage that they could not bring themselves to sue.

Adult-child caregivers often expressed great ambivalence about using up the parent's financial assets for nursing home care or contributing support themselves. Some expressed relief that the parent was able to afford good care so that they would not have to take money from themselves and their own families, yet many children disliked the prospect of the parent going on Medicaid. In other cases where adult children did contribute financial support toward the institutional care, they felt caught in a terrible bind between choosing whether to spend on their parent or on themselves, their own children and spouses, or their own future retirement.

Dilemmas Related to Autonomy

Ethical dilemmas pertaining to autonomy and paternalism have received considerable attention in the biomedical literature (Gadow, 1980; Moody, 1985; Meier & Cassel, 1986; Wetle, 1985a), yet little is known about these issues from family members' perspectives. We do not know, for example, how family caregivers assess the elder's competence to make decisions, nor what their beliefs are about who should participate in placement decisions, with what degree of influence, and under what conditions.

In our studies, we found little evidence of elders' participation in nursing home placement decisions. Only three (4%) of the 67 institutionalized elders were reported by the caregiver to have had the final say; another 12 elders (18%) were consulted, but someone else made the final choice. The remaining 52 elders (78%) did not participate at all in the decision, according to the caregivers. In the 64 families where the elder did not have the final say over institutionalization, the primary decisionmaker was the elder's spouse

(n=12), a daughter (n=23), son (n=11), daughter-in-law (n=1), physician (n=1), or the caregiver reported there was no one person who had the final say (n=16).

Only five (8%) of the 67 families reported that the placement decision was made by a single person. The number of people participating in the decision ranged from one to thirteen (mean=4.04). In the majority of families, other family members were always, usually, or occasionally consulted about the institutionalization. Most-frequently mentioned auxiliary family decisionmakers were the elder's spouse and children, followed by daughters-in-law, sons-in-law, and granddaughters, then miscellaneous other relatives. Professionals were rarely reported as participants in the decision.

When the elder did not participate in the placement decision, physical and/or mental impairment was usually cited as the reason. In other cases, however, delegation or abrogation of the elder's decisionmaking autonomy was described as either part of a longstanding pattern of reliance on others to make decisions or a moral necessity from the caregiver's point of view. As one son commented, "I didn't ask my mother's advice. It was imperative she have fulltime help. She was told about it and accepted it."

Four out of ten (39%) of the children and one out of ten (14%) of the spouses in our studies reported difficulty getting the institutionalized elder to accept the fact that placement was necessary. In addition, several of the caregivers reported that, prior to the elder's placement, they or another family member felt that the elder should enter a nursing home, but that the elder refused.

In sum, placement decisions confront family caregivers with difficult dilemmas related to autonomy and paternalism. For example, should the elder

have the right to choose to enter or not enter a nursing home when caregivers disagree with the elder's choice? Who should participate in the decision and with what degree of authority? Conversely, who, if anyone, should be excluded from these decisions and on what basis? What role ought professionals and other non-family members play in placement decisions? Under what conditions is the paternalistic assumption of decisionmaking authority by family caregivers morally justifiable? Can an elder's decision to enter a nursing home truly be an autonomous one--that is, an individual choice made voluntarily, intentionally, and without undue influence--given the elder's dependence on others for care and the institutional bias in services and reimbursement (Moody, 1985; Wetle, 1985a, 1985b)? Given evidence that participation by elders in institutionalization decisions enhances their subsequent adjustment (Brody, 1977; Chenitz, 1983; Kasmarik & Lester, 1984; Noelker & Harel, 1978), are caregivers morally obligated to include the elder in decisions even if this complicates or impedes the decisionmaking process?

Differences Among Family Caregivers

While disagreement between elder care recipients and family care providers raise important ethical dilemmas related to the elders' autonomy and caregivers' paternalism, these were not the only differences evident in our studies. We found many instances where caregivers disagreed among themselves about such matters as the severity and nature of the elder's functional limitations, the feasibility and desirability of various home care options, the willingness or ability of various family members to provide care, and the need for institutional placement. One of the most dramatic cases was a family where the elder's husband and two children reported that institutionalization was needed because

of the elder's Alzheimer's disease, while a third child felt her mother simply feigned confusion to get attention, saying her mother had always been a difficult person.

Such differences pose difficult dilemmas for family members and other caregivers about how discrepant perspectives ought to be handled, yet this issue has received little attention in the bioethical literature. For example, is it preferable to acknowledge and confront such differences or is it sometimes better to ignore them? When differences arise, should all family members' opinions carry equal weight or should the primary caregiver's opinion be the determining one?

The Quality of Family Relationships

The clinical social work literature on institutionalization has raised a number of ethical issues regarding the impact of the quality of family relationships on placement decisions. For example, the ability of family caregivers to represent the best interests of the elder, to weigh possible alternatives to institutionalization, to assess the appropriate timing for placement, to provide or obtain the home care assistance needed to prevent premature placement, and the ability to assume decisionmaking responsibility when necessary may be undermined by longstanding family conflicts or maladaptive family roles (Alan, 1984; Brody, 1977; Chenitz, 1983; Knight & Walker, 1985).

Our studies provided many illustrations of such dilemmas. For example, some caregivers wanted to avoid institutionalization, but cited the elder's difficult, demanding personality as one of the reasons why home care could not be sustained or why living with the parent was not a viable alternative. In other cases, institutionalization was sought specifically as a means of avoiding

family conflict or erosion of the relationship between caregiver and care recipient. Particularly for the families caring for Alzheimer's patients, changes in the elder's personality and deterioration in the elder's ability to relate to others were major factors in the placement decision. Problems in family relationships were also frequently mentioned in our studies as reasons why some family member did not participate in the placement decision or why, if they did participate, the decisionmaking process became complicated or unpleasant.

These issues related to family relations touch on ethical concerns such as paternalism, the ability of family members to make beneficent choices, and conflicts of interests among family members. They also raise the question of whether we ought to take into account the quality of family relationships in defining family responsibilities (Callahan, 1985). The experiences of the Community Services staff at the Rose Institute clearly indicate that the interaction between family relationships and placement decisions is a complex one, however, with estranged or conflictual relationships sometimes hastening placement and other times delaying it.

Conclusions

In sum, there are a host of ethical dilemmas which family caregivers potentially face in making placement decisions. This paper has examined dilemmas arising because of difficulties inherent in defining what is best for the individual elder; problems in delineating caregivers' responsibilities toward the parent or spouse; conflicts of interest or competing obligations; policies, services, and reimbursement mechanisms for long-term care; tension between such values as autonomy and paternalism; different perceptions among caregivers; and the quality of family relationships.

We clearly have much to learn about how, when, and why placement decisions occur. For example, does placement involve one clear decision or many interlocking choices? Are these decisions made relatively quickly or over extended periods of time? Is the process a fairly rational one or not? What factors precipitate and shape placement decisions? What help, if any, do family members want when making such decisions? How are placement decisions affected by the elder's impairment?

If we are truly to understand the dilemmas family caregivers face in making these decisions, we also need research which explicitly and systematically focuses on ethical issues. Placement decisions, however, are only one of many long-term care choices people face, and we need to ask in what ways, if any, the ethical dilemmas are different when institutionalization is involved. Another major issue which needs to be addressed is the ethical implications of qualities of family relationships such as family history, emotional bonds, and interdependence, which current perspectives often ignore (Gilligan, 1982; Moody, 1985). Lastly, we should consider ways to ease the dilemmas which families must inevitably face in placement decisions, as well as ways to prevent those dilemmas which are not immutable. Whose responsibility this ought to be, is itself an ethical issue.

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